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Dear Special Commission Members:

Thank you for this opportunity to submit written comments regarding the Special Commission on the Health Care Payment System's implementation strategies and payment models. In our qualitative research report and below we highlight the health care barriers faced by individuals with intellectual and developmental disabilities (ID/DD). This patient population's health outcomes and costs should be considered in discussions of health care system or payment reform.

Considering this population is smart planning due to the following reasons:

- there is an aging population of individuals with ID/DD with many chronic illnesses
- individuals are forced to access medical care through emergency room settings
- failure to identify problems early and the poor management of chronic illnesses may increase our overall health care costs.

Four out of the seven key findings or themes in our research report directly relate to the Special Commission's mandate: care coordination, insurance, quality of care, and access.

- a. Because of haphazard care coordination practices for adults with ID/DD, individuals miss scheduled appointments and/or do not follow up on health treatment plans (lab work, filling prescriptions, paying medical bills, scheduling appointments, etc). The lack of care coordination is a major barrier because of the inability of some adults with ID/DD to effectively recognize, understand, communicate, and advocate their health care needs.
- b. Due to low reimbursement rates, individuals with ID/DD and their caregivers or providers have difficulties locating health care professionals who accept publicly insured adult patients. Typical or routine visits with this patient population are not short. In turn, some individuals with ID/DD are referred to emergency rooms (ER).
- c. Patients with ID/DD are told to go to ERs because of the shortage of community health care professionals who are knowledgeable and equipped to deal with specific health care and mental health needs of this patient population. After entrance into the ERs, individuals are released and re-enter the ER within a short period of time – sometimes the following day. Respondents reported that individuals in hospitals may be abruptly discharged before the weekend if doctors realize there will be no reimbursement for the weekend. Patients are improperly discharged without adequate supports in place and sometimes sent back to emergency rooms.
- d. As mentioned previously, due to advancements in medical technology, individuals with ID/DD are living longer and have multiple health conditions, such as chronic disease. A high percent of individuals with ID/DD present complex health conditions, which require access to multiple health care specialists and other providers. Despite this fact, individuals with ID/DD lack proper and preventative health care, such as routine

physical examinations (some never even are weighed due to lack of equipment) and cancer screenings.

Addressing both this population's health care needs and the report's findings would result in more effective use of the health care system's funds. Three of the report's six recommendations are to

1. Develop and provide formal care coordination for all adults with ID/DD. Implementing the medical home model for individuals with disabilities – including children, youth, and *adults* with ID/DD – would improve quality of care and provide preventive primary health care through measures of enhanced communication and coordination between patients and their families, staff, and health care providers (comprehensive, primary, and patient-centered care).
2. Reduce reimbursement barriers of health care professionals and community support staff. Restructuring reimbursement rates would increase patients' access to preventive care – not ERs. Rates must reflect actual time spent providing high-quality medical care to this patient population. This will require collaboration between health care professionals, insurers, and health systems to determine how current billing codes could be used without creating unintended consequences.
3. Improve access to high-quality care at medical practices and hospitals. Establishing safeguards for medical practices and hospitals regarding admission, discharge, and treatment planning for individuals with ID/DD would reduce improper, speedy discharges and increase patients' quality of care. Safeguards would also save the health care system money in the long-term. In addition, the availability of primary care physicians and other health care professionals must be increased through various strategies, including special insurance programs, reimbursement schedules, and outreach.

Again, an increasing number of individuals with ID/DD are living longer with chronic illnesses and continue to face multiple barriers and obstacles in terms of accessing proper preventive care. Implementing the above recommendations would provide an avenue so that more individuals with ID/DD could access preventive high-quality health care – and many chronic diseases are preventable – rather than reactive, poor quality – and more expensive – care through ERs. Less costly, preventive health care services are an integral component of comprehensive care that would reduce the current, astronomical costs of the health care system. Poor management of chronic illnesses, along with this patient population's current improper utilization of health care services, certainly contribute to the most expensive and rising costs of the health care system.

Sincerely,

Mandy Nichols, Director of Health Care Policy

Leo V. Sarkissian, Executive Director

Inserted on the next page are four of our report's findings for your review. If you would like to examine the additional identified barriers or findings, please access the full report through the following link:

<http://www.arcmass.org/ArcMassHome/WhoWeAre/ServicesatTheArc/HealthCareProject/HealthCareProjectReport2009/tabid/848/Default.aspx>

## **Insertion of Report's Findings:**

### **VI. CARE COORDINATION**

Care coordination is not a standard practice for patients with intellectual and/or developmental disabilities (ID/DD). Although parent/guardian and community support and health care professional respondents had varying definitions for care coordination, they all felt as if care coordination was lacking. For some participants, care coordination was about formal processes that helped patients navigate the health care system. For others, care coordination involved informal systems or individuals who stepped in from time to time to facilitate connections between health care providers and patients. Regardless of the formal or informal attributes of care coordination, it was noted by many respondents that the complex nature of the health care needs of patients with ID/DD warrants a more sophisticated level of care. In addition, the health care professional interviewees identified good models of care coordination.

#### ***Informal care coordination***

Although self-advocates were not able to identify professional components of care coordination, they revealed informal practices they sometimes sought in order to receive help with their medical needs. Most often, self-advocates asked for or received help from family members, neighbors, friends, and/or service coordinators. These individuals performed various tasks: (a) paying medical bills, (b) making appointments, and (c) filling prescriptions. In one instance, a self-advocate described how a neighbor took matters into her own hands and worked out a solution to his medical needs.

*Yeah, Mike's [alias name] wife. These are the people that lived on the second floor under us ... And when she heard about this, she kissed me because I'm like family to her. And so she took—She says, "Martin [alias name], stay, and I'll take you. She took me down herself, and not only that, they took care of the problem that day. (Self- Advocate)*

Parents/guardians commented that when their adult son or daughter received medical care from pediatric health care professionals, care was almost always coordinated. However, since transitioning from pediatric to adult care, all parent/guardian focus groups reported that they experienced a fragmented system of care in the adult medical care system.

*There's a care coordinator in the [pediatric] office[s]. ...I think that makes a huge difference in the kind of care that kids get, and I don't see why it wouldn't work for adults, for this population." (Parent/Guardian)*

*I think the biggest problem for us, for the parents especially as we're getting older, is the system is so fragmented, the adult system. We were used to a system where the issues were coordinated by the medical profession and you could speak to a team, everything was a team effort. And suddenly, they reach the adult world and it's not. It's not, it's an individualized thing. So, I think that the thing we have to really strive for...is to almost force the doctors to work as a team. Now, it took us quite a few years to do that, but we got a team of people that talk to each other. (Parent/Guardian)*

Parents/guardians who found a missing or fragmented system of care in the adult medical care system stepped in to coordinate their adult son's or daughter's medical care. Parents/guardians reported juggling phone calls and various medical appointments.

*...I think I have three or four envelopes just on maintaining it [insurance applications and bills], plus the yearly physicals, the yearly dental visit, [there are] so many things in managed care. (Parent/Guardian)*

Balancing a patient's medical needs is a very difficult task. As such, parents/guardians who assume the role of care coordinator can sometimes feel overwhelmed.

*...in the meantime, I'm a parent. I have an allergist, a dermatologist, a gastroenterologist, a[n] urologist, a pediatrician. I don't know if there's something I left out-- a psychiatrist and a dentist. And I have respite staff I'm managing at home. ... And I am looking for my fifth behavioral consultant. (Parent/Guardian)*

### **The need for formal care coordination**

Three community support professional focus groups and some health care professional interviewees also expressed a need for care coordination. Patients who do not have an individual to act as their care coordinator sometimes missed scheduled appointments or arrived for appointments that had to be rescheduled due to a breakdown in communication between providers.

*Another story is about a situation with [a] residential provider who set up [a] psychiatric meeting but left [the] service coordinator (regional Department of Mental Retardation [DMR] case manager) out of loop, which meant a second meeting with consult[ants] had to be set up since all information hadn't been gathered (day, residential, and family); this type of thing does happen due to staff from home or day program[s] holding back information and not coordinating. (Community Support Professional)*

*We just want to make sure they [patients] can keep their appointments.... And coordinate their care with other specialists. (Health Care Professionals)*

In situations where community support or health care professionals played the role of care coordinator, they found themselves assuming the role of detective, advocate, educator, and/or liaison. In some instances, these professionals had to demand services from different providers.

*You have to advocate for them. You sometimes even have to fight for them, basically. (Community Support Professional)*

Many health care professional interviewees stated the need for care coordination because they did not have the time to perform the service. Care coordinators were described as persistent and consistent and viewed as the crucial piece needed in the adult medical world to reinforce coordinating care – e.g. follow-up on referrals, prescriptions, and lab work – for patients with ID/DD living with their families and in group homes.

*I think sometimes when you have someone, when you have a family that is not very involved whether because of problems in the family or because, you know, the patient is older and the parents have passed on, or because the patient has been institutionalized, [then] there is usually less than adequate follow-up in the patients... [They] need support from others in order to be able to carry out...recommendations with another physician. (Health Care Professional)*

### **Strategies for care coordination**

In the health care professional interviews, some respondents mentioned other programs that used good models that emphasized care coordination.

*...Commonwealth Care Alliance has been designated through Medicare Part D to be a special needs program. This is a specific program whose foundation is care coordination. They can develop networks and either provide the nursing coordination from their own base or they can*

*have health centers or other practitioners work with them to do care coordination. (Health Care Professional)*

*Personally I use [the] volunteer advocacy program [at BMC] and at this point I have an advocate involved with all of my independent patients. I can say to the advocate, can you meet so and so and walk them over to cardiology to see whether they do have an appointment and make sure they get in and all that stuff. (Health Care Professional)*

A few of the health care professional interviewees who were familiar with the challenges patients and families faced as they entered or continued in the adult medical care world implemented their own systems of care coordination. In some instances, health care professionals assigned a staff member to act as the liaison between patients and other providers.

*To be honest, nothing worked well until I had our care coordinator because adult doctors and pediatricians are never trained; we're never given any information on what's available as far as ...the care coordination [piece].... The parents will come to me and say what do I do? They'll say I don't understand what I have to do next. That is what very much triggered me to hire our care coordinator to have her become a specialist in all these areas to help the families. This has proven to be extremely helpful not just to me, but obviously more so [for] the families themselves. (Health Care Professional)*

## **V. INSURANCE**

Insurance coverage alone does not guarantee access to qualified health care professionals and necessary medical services. Insurance barriers were identified across all focus groups. Self-advocates, parents/guardians, and community support professionals revealed two salient concerns: patients experience difficulties accessing medical care due to the differences in types of health insurance coverage and patients experience difficulties obtaining needed medical care services due to the service gaps in health insurance coverage. In addition, health care professional interviewees echoed the shortage of health care professionals and attributed one of the causes to low reimbursement rates. Furthermore, parents/guardians identified their lack of understanding of the insurance system as a key issue.

### ***Shortage of health care professionals accepting public insurance***

Adults with intellectual and/or developmental disabilities (ID/DD) and their caregivers or providers have a difficult time locating health care professionals who accept patients insured through public health coverage, such as MassHealth (Medicaid). Respondents across all focus groups struggled to find qualified and knowledgeable health care professionals who accepted new adult patients insured through public coverage.

*The problem, too, is that our folks are on MassHealth, and that a lot of the primary care providers that I'm calling aren't taking MassHealth. (Community Support Professional)*

*I noticed that in most cases, they wouldn't take MassHealth. (Self-Advocate)*

Some respondents reported choosing a health care professional based solely on their willingness to accept publicly insured patients. Many of those respondents reported that health care professionals who accepted MassHealth tended to have limited knowledge and experience working with the ID/DD population. The inadequate number of MassHealth health care professionals created additional logistical and geographical obstacles for some respondents.

*Some of them said, Yes, I take MassHealth, but I won't take adults. [Others said,] Yes, I take MassHealth, but I only take certain disabilities. (Parent/Guardian)*

*It's hard to find enough doctors...as well as MassHealth physicians. I searched to find a doctor 40 miles away that, finally, was accepting MassHealth patients. Everybody seems to be maxed out and not accepting MassHealth clients. (Community Support Professional)*

Other respondents were left without appropriate and timely specialty medical attention because health care professionals, ones they were referred to or located on their own, would not accept their type of insurance coverage.

*...the dermatologist that we had to make an appointment with wouldn't make an appointment because the [reimbursement] rates were too low, they didn't take MassHealth clients. So we [my daughter and I] had to wait another two months with a mole that could have been a melanoma; thankfully it wasn't. (Parent/Guardian)*

Some respondents reported that their health care professional had once accepted publicly insured patients, but then suddenly dropped those patients due to dissatisfaction with the insurance process and/or reimbursement rate. In turn, these patients and their families were responsible for beginning the search for and finding another health care professional.

*We got a letter one day [from our doctor's office] that ... [stated that they were not taking MassHealth patients any more]. [I] called the doctor, ...[and] said I'm willing to pay for a while until I find somebody else, just keep—[They said,] No, we don't want any part of it. [I said,] Well, does your — [And they said,] No, we don't want any part of it. (Parent/Guardian)*

Many community support and health care professional respondents identified the extremely low reimbursement rates set by insurance companies as a key barrier. These respondents said that the ID/DD population requires more in office time; thus, reimbursement rates should be adjusted to reflect the additional time needed to provide appropriate care.

*Typically visits [with individuals with ID/DD] are not going to be short. Even the sick visits are much longer than the usual. I think it is true for a lot of physicians that it's not worth it from a time perspective point of view. (Health Care Professional)*

*...it does take more time. It is more work. And they [health care professionals] probably wouldn't be so averse to it [seeing patients with ID/DD] if they were reimbursed properly for the time it's really going to take. (Community Support Professional)*

*If the patient is covered by MassHealth, the [dental] reimbursement rates are much lower—about 1/3 to 1/2 lower. (Health Care Professional)*

In addition to the extended time needed to properly care for patients during medical appointments, some community support and health care professional respondents reported that caring for patients with ID/DD requires additional administrative time for follow-up or care coordination and time-consuming billing issues: lengthy waits for reimbursement, e.g. up to one year, and difficult and challenging billing processes. These disincentives caused some health care professionals to drop publicly insured patients and others to set caps on the number of patients with ID/DD on their panel.

*...some of them, I don't receive payment ever. They don't have the correct family care provider, or for some reason or another, things just don't work out. It's a loss. (Health Care Professional)*

*Systems started to change and we were demanding more paperwork and he [doctor] wasn't willing to... [do a] new way of ... business. (Community Support Professional)*

To provide necessary medical services, a few of the health care professional interviewees – those who were very knowledgeable of the ID/DD population – were creative when it came to coding their performed medical service. This creativity allowed the health care professionals to receive reimbursement for the medical services they felt their patients needed.

*...sometimes you have to choose a diagnosis to justify a certain blood draw...it doesn't always fit the paradigm available...For example, for [individuals with] Down syndrome it is very common for them to have hypothyroidism, so it's routine that you check...and it's recommended that you check, a minimal screening of TSH every year. Also it's crucial to check for vitamin B12 because it's pretty common they have deficiency. If Down syndrome is the diagnosis ... [and] the reasoning [for testing] is for TSH or B12, then Medicare wouldn't pay for it because they don't consider Down syndrome a reason to get TSH. I leave in the diagnosis for Down syndrome, but for the TSH I have to put in another reason to get it. Like if they have chronic constipation, I can use constipation as a reason to get the TSH. You can find other diagnosis that the patient might have to justify the TSH. (Health Care Professional)*

### **Lack of adequate insurance coverage**

In addition to a deficiency in the number of knowledgeable and appropriate primary care providers, respondents identified several specialty areas that were also deficient: sign interpreters and language translators; nontraditional screening procedures; adaptive equipment; medications; and mental health, dental, ophthalmology, and mammography/gynecological health services. Other insurance constraints revolved around limits on the number of times patients could receive certain medical services within a one year period, for instance it was reported that MassHealth has stringent limits on psychiatric and dental visits in a one year period.

*It's unfunded. Medicaid should truly pay for the [sign language] interpreters, because we can't have [health care] access without it. ...it's just a simple reality. (Community Support Professional)*

*... MassHealth won't pay for [a] CAT scan if a person is unable to go through with a mammogram. (Community Support Professional)*

*I have had three cases of breast cancer and one case of rectal cancer in the past year because the persons were afraid of or unable to complete a "traditional" screening and MassHealth would not pay for other screening. (Community Support Professional)*

Because of gaps in coverage, some individuals and families were forced in to difficult financial constraints. One self-advocate and all parent/guardian focus groups identified costly co-pays and/or out-of-pocket expenses as a significant problem. In turn, some of the adults with ID/DD went without needed medical services.

*[I am] not going to have [cataract] surgery because [I] can't afford it. (Self-Advocate)*

*...it's our wages. ...I'm going to give ... [a psychiatrist] \$150 dollars, and then ... pay for the medicine too? (Parent/Guardian)*

### **Lack of consumer knowledge of insurance system**

Some parent/guardian respondents reported a lack of understanding of the insurance system as a major barrier. They reported facing many difficulties as they navigated the insurance system. Moreover, some respondents felt stigmatized by difficulties experienced using public health insurance.



*The [insurance] conversation makes my head spin. (Parent/Guardian)*

*...if you have private insurance and you pay for the insurance, [does] that means the doctor would take care of you better [when insured by private coverage rather] than having MassHealth or having free care? (Parent/Guardian)*

### **III. QUALITY**

Appropriate and positive attitudes, interactions, and processes performed by health care professionals and residential staff were essential to receiving high-quality medical care. Across all self-advocate, parent/guardian, and community support professional focus groups, two salient categories were identified: poor and good quality medical care.

#### **Poor Quality Medical Care**

Every focus group and members from each grouping<sup>1</sup> identified different types of negative experiences resulting in poor quality medical care. The five main themes identified were (a) bias about and insensitivity to patients' needs, (b) lengthy waits and rushed medical practice atmosphere, (c) negative impact of quality of care based on patients' behavior, (d) inadequate medical care received by patients, and (e) lack of resources.

#### ***Bias about and insensitivity to patients' needs***

All self-advocate and parent/guardian focus groups pinpointed different ways that health care professionals, including office staff, were insensitive to patients' needs. It seemed that some of the poor medical care and attention received was connected with negative attitudes and beliefs about individuals with intellectual and/or developmental disabilities (ID/DD) and their overall health and quality of life.

*I get a phone call from her [secretary at the doctor's office] saying pay the \$3,688.99. [And I said,] But I don't have that kind of money. [The Secretary said,] Okay, you're not coming back anymore, you're not coming back. (Self-Advocate)*

*What I find that is often uncomfortable and awkward is the types of things that they [health care professionals] will talk about in front of him [son] with me. ...his behavior, they will ask me about that-- embarrassing for him.... And most of the time, they won't even ask or acknowledge that this may be awkward... [or say] could we do this in a different way? (Parent/Guardian)*

*I made the mistake of saying that she was at Perkins School for the Blind in a behavioral [program].... So what happened was the nurse and the doctor stood at the door and I held my daughter in my arms, took her temperature, helped with the BP cuff and nobody actually came and touched her. (Parent/Guardian)*

Self-advocates' and parents/guardians' accounts were supported by community support professional respondents.

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<sup>1</sup> Grouping include all self-advocate, parent/guardian, and community support professional focus groups



*I've met people who have had cataracts that needed to come out. And the doctor didn't see the need, because the person didn't read.... (Community Support Professional)*

### ***Lengthy waits and rushed medical practice atmosphere***

Across all self-advocate and parent/guardian focus groups, lengthy waits and untimely appointments, both in emergency rooms and medical offices, were identified as insensitive and not conducive to patients' medical needs. Irritation arose from some respondents after lengthy waits; some patients walked out of waiting rooms before they were seen by nurses or doctors.

*Scheduled appointments, they make you sit there for three or four hours. .... You should take me at 12:00. Instead, they make you wait four or five hours. They don't care if you die in their waiting room. (Self-Advocate)*

*...how dare you make this person, who my doctor had already called to say he was coming, make him wait? [The receptionist said,] Well, the emergency room is filled. I said, I don't personally care if it's full. I said, Can you see the behaviors he's having? He is a wreck. So I whispered in his ear, calmed him down, and they saw him right away, but it was a nightmare. (Parent/Guardian)*

A good number of respondents felt some patients' medical needs were not fully understood because medical visits were rushed (highlighted previously in communication finding section) and some health care professionals did not take time to build relationships with patients before performing medical procedures. In turn, some respondents were reluctant to schedule future medical visits.

*Sometimes when you get to the hospital, you don't even sit down very quick. He is already writing a prescription. (Parent/Guardian)*

*...how...they interact with her when she's sitting in a chair. I watch everything. So that experience, you're just not in a rush to go...again. So we just pushed that [dental] appointment off a little bit more.... (Parent/Guardian)*

Others "pushed back" appointments and went without medical care attention due to the lack of alternative and more comfortable medical procedures and forms of screening.

### ***Negative impact of quality of care based on patients' behavior***

Three parent/guardian and four community support professional focus groups pointed out that some health care professionals had negative assumptions about patients with behaviors, did not know how to care for these patients, and/or feared for their safety or that of others.

Some respondents reported that patients were labeled as difficult and sometimes went without needed medical services, e.g. preventative and routine screenings, because of behaviors while others were heavily sedated in order to receive medical care. Some patients were referred to emergency rooms because medical offices were not trained or equipped to work with them.

*...we had three week trials for our daughter at Tufts many years ago, and all it was [was] a cleaning, and every time she came in, she was fussing so much, they [dentist] said, she's not cooperating, [and] you'll have to make another appointment. We did that three times in a row. (Parent/Guardian)*

*...they [health care professionals] will say not cooperative. Re-see in two years. Well okay, so if that keeps going on; and, of course, I've done, in my career, lots of historical eye exam*

*report studies, you can go back, and the person was not cooperative for five of their past visits, which translates into 10 years. (Community Support Professional)*

Some respondents stated patients' behaviors were sometimes vital to uncovering and validating a medical condition as well as figuring out the medical problem, especially with patients who were non-verbal. Others questioned if behavioral protocols were available to all health care professionals.

*Behavior[al] changes are often overlooked that can indicate [a] health issue i.e. bathroom frequently, fever, increase in aggression and anxiety, pacing, humming, increase [of] injuries. (Community Support Professional)*

A few of the respondents reported patients who were prescribed new and different medications aimed at correcting those behaviors.

*The medication isn't doing anything at all.... [They keep] putting the dose up and up. All medications, he's been on it. (Parent/Guardian)*

### ***Inadequate medical care***

Across eight focus groups<sup>2</sup>, many respondents identified that some patients had received incomplete or inaccurate medical care services. Some patients did not receive "normal, routine" medical exams and timely, proper medical treatment.

*The doctor said, well, we can't do any more for her. She needs to go home [Puerto Rico], like to die. ...that's why she made the decision to go to Puerto Rico to take her [daughter] to the church, [so] that she should go there and one of the pastors pray for her and [the pastor] told her to take her [daughter] to the hospital. She had to leave the United States where there is more help here to go to another country to be able to save her daughter. (Parent/Guardian)*

*So they're [doctors] not really receptive to creative solutions to enhance their care and give extra tests, you know, the regular tests that all of us have as we reach adulthood for preventative care, whether it's bone density or mammogram or colonoscopy or whatever. And I just found that I run into that a lot. (Community Support Professional)*

*I had a woman who had a heart attack, and the ER made us [wait] in the waiting room for three hours. The woman almost died because of the hospital's neglect. (Community Support Professional)*

Some respondents stated that patients did not receive adequate medical care because forms were not filled out properly. Four community support professional focus groups reported the difficulties collecting state mandated medical forms – mainly for individuals living in residential homes – from health care professionals, and one self-advocate group in Boston described their difficulties collecting forms, including those needed for non-medical services.

*Oftentimes they [health care professionals] don't want to give us that time that we need in order to have them fill out our forms. There [are] a lot of things that come up in the course of working with a doctor that they need to sort of accommodate our requirements that are caused by the state. A lot of doctors just won't do it. (Community Support Professional)*

*She [health care professional] never mailed it [transportation form]. She never filled it out and mailed it back. (Self-Advocate)*

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<sup>2</sup> The groups include three parent/guardian and four community support professional focus groups and one mixed focus group of community support professionals and parents/guardians

The lack of appropriate accommodations, such as examination tables that lower to the floor, in medical offices were identified by two parent/guardian groups as poor quality and incomplete medical care for patients.

*There's no way for them to weigh my son, they have no idea how much he weighs. There's no way to weigh him. (Parent/Guardian)*

Improper, speedy hospital discharges was identified by three community support professional focus groups as incomplete and partial medical care. This resulted in problems when (a) discharge summaries and recommendations were not received by those who cared for the patients and (b) in-home supports were not in place. Without notice and by ambulance, some patients were discharged on Friday nights. In these instances, many respondents reported that patients usually returned back to the hospitals' emergency rooms within a short period of time. Sometimes, the discharge summary would order patients to be returned to places, e.g. nursing homes, where they did not reside.

*...the doctors get it together and realize there isn't going to be reimbursement for the weekend, so they want them out. ...unprepared and very often they're back in the ER by Saturday.... (Community Support Professional)*

*I had a client that was in the hospital, admitted. They discharged him, sent him back to the group home one Saturday evening and notified nobody. (Community Support Professional)*

### **Lack of resources**

Across four community support professional focus groups, many respondents identified the lack of available resources of agencies and community programs, e.g. residential, as having an affect on the quality of medical care for those patients who are served by them. Funding seemed to be lacking and resources looked as if they were spread thin and squeezed to fit the needs of all clients.

Some respondents reported residential staffing shortages. Residential managers were sometimes forced to send relief direct care staff and/or fewer staff than needed to medical appointments with patients.

*Sometimes it's just about the disability. If a patient is 200 pounds many [health care professionals] will say to the patient, don't take your clothes off for the exam simply because there is only one staff and the [medical] provider doesn't want to lift them. (Community Support Professional)*

*When I hear about somebody coming out of a psychiatric admission and going back to their psychiatrist, and I hear that they have gone with the relief staff, somebody who's never met that person before, and this person had been hospitalized because they were in crisis, first thing I say is there's something really, really, really wrong with that. And it's not the doctor. So we need to care about the people that we support enough to provide a proper advocate for that person. (Community Support Professional)*

*After going back and forth with them on several people, now, it came back that the hospital was baffled that we don't have... a nurse in every [group] home. ...it's their perception. Their perception is off. (Community Support Professional)*

The lack of resources available at medical offices also affected patients.

*...it's true, there's a lot of duplication, there's a lot of that extra work that's often required of a doctor. (Community Support Professional)*

*If we can't get our own interpreter, we will actually do an appointment without an interpreter. ... [We] absolutely don't want to do it, but we will do it. Our nurse [in our program] does sign, although she's certainly not going to be interpreting. But she can sign, so there [are] aspects. And obviously, our staff has good skills. But that's your lowest bottom. (Community Support Professional)*

## **Good Quality Medical Care**

Overall, two self-advocate and three parent/guardian focus groups reported different types of positive experiences resulting in good quality medical care. One main theme emerged: satisfaction with overall practice atmosphere.

### **Positive practice atmosphere**

Some of the self-advocate and parent/guardian respondents said they felt welcomed when members from the medical offices treated them with respect. Those health care professionals were identified as “terrific” and “phenomenal.” A few self-advocates reported happiness with their health care professionals, particularly due to the direct communication with and involvement of patients.

*He treats me wonderful and everything else. He always controls the paperwork, controls everything. He holds nothing back.... (Self-Advocate)*

*...they took him for another emergency, everybody was on.... [There was a] ... nurse... [and] two doctors in the room.... And everyone was saying, Sam [alias name], stay here with us. They were wonderful. ... it's who's on duty; it's how busy the ward is.... (Parent/Guardian)*

Across two parent/guardian focus groups, some respondents pointed out health care professionals who spent the necessary time during and outside of appointments to attend to their adult sons'/daughters' medical needs. Some respondents reported patients who did not need to be restrained or medicated because they became comfortable with their health care professional. A smaller number of respondents reported some health care professionals were sensitive and displayed patience during medical appointments.

*[The doctor] opened the record, and I felt as if there was no one in that waiting room. She proceeded to leaf through the pages and ask us very appropriate questions and was as gentle with him on all his vitals, and I felt I was there to assist, and I literally was there, took it all in as an observer. I would recommend anyone [to] see her, she was phenomenal. I'm just hoping she stays in the area...she is great. (Parent/Guardian)*

Many of the parents/guardians took it upon themselves to educate the health care professionals of the need to slowly accumulate themselves to the patient (as previously touched on in the knowledge section), and some reported health care professionals who were receptive to that message.

*When I went there [new dental office], I talked with the receptionist. ...I said that two of my sons have special needs. ...that's basically what I told them [receptionist and dentist], ... [that] they're shy, and he [one of my son's] will get real defensive if they [the dentist] do[es]n't explain to him, first, what they're going to do. (Parent/Guardian)*

Respondents from two parent/guardian focus groups identified some health care professionals who had accommodated to their adult sons'/daughters' needs. The positive experiences were associated

with health care professionals who had flexible appointment times and learned to adjust their practice in order to accommodate patients.

*And now she has a new doctor, we've only been going to her for about eight or nine months, but she has been wonderful. She takes Sara [alias name] in right away and there's no lingering. (Parent/Guardian)*

*Actually, our dentist accommodates us by giving her the first appointment in the morning. He knows [to see her] before anybody else because she would scream [while waiting] anyway. (Parent/Guardian)*

*...the hospital has been fantastic in how they [have] treated him. ...he had to have anti-seizure [medication], [so] we stayed with him for every minute. Then he had to stay overnight to be prepped for the colonoscopy. They had what they call a sitter so we didn't have to stay all night with him. (Parent/Guardian)*

#### **IV. ACCESS**

The ability to access timely preventative and as-needed medical services was vital and very important to all groups. Across self-advocate, parent/guardian, and community support professional focus groups and health care professional interviews, respondents reported the barriers faced while attempting to access medical care. The three key categories identified by the respondents were (a) problems finding health care professionals, (b) adults with intellectual and/or developmental disabilities (ID/DD) who continue to remain with their pediatricians, and (c) lengthy waits and delays experienced after locating health care professionals. However, positive experiences of accessing medical services were described by one group (parents/guardians).

##### ***Problems finding health care professionals***

One self-advocate, all parent/guardian, and three community support professional focus groups and some health care professional interviewees reported the difficulties of locating health care professionals as a salient barrier when attempting to access medical services. For various reasons, all groups identified health care professionals, including primary care physicians (PCPs) and/or medical care specialists, as difficult and challenging to find, especially since there were only a limited number of adult health care professionals.

*...it is a barrier to find a physician for them. If an adult patient decides to move to an adult provider [and]... find internal medicine or family practitioners who have an interest in this population, I have found [that to be] very difficult – in my area at least. (Health Care Professional)*

*It was very limited what I could find out there, who understood autism and [the] family, the whole dynamic of my family. (Parent/Guardian)*

Across focus groups and health care professional interviews, multiple respondents reported difficulties in finding medical and non-medical care specialists, including dentists, gynecologists, mental health specialists, dermatologists, ophthalmologists, sign interpreters, and language translators. These specialists were even more difficult to find if immediate medical attention was needed. As a result of these difficulties, sometimes timely medical treatment was not available.

*Well the huge, the biggest issue, which is obviously no surprise to anybody, is ... [the] issues with mental health – behavioral support – it's just not there. (Health Care Professional)*

*If I have an adult who has development disabilities and they're not on MassHealth, [then] I have no problem getting referrals to general dentists. I can refer them to Mass. General. But the minute they find out that ... [the patient is insured by] Mass Health, I can't do it. (Health Care Professional)*

In addition to the limited number of available health care professionals, other difficulties faced during the search process were identified by many respondents. These barriers related to health care professionals who would not (a) accept MassHealth, (b) work with adult patients with ID/DD, and/or (c) accept new patients into their practice.

*[There is a] lack of specialists on the adult level who are comfortable and skilled in treating adults with ID/DD. Pediatricians are trained to work with children with disabilities, but not adults. Some do not want to work with adult medical problems. (Health Care Professional)*

To further compound the search, a mix of additional obstacles was faced by many respondents when trying to locate health care professionals. Those barriers included the health care professionals' lack of experience, inflexible appointment times, inaccessible equipment, unfit examination rooms, inaccessible buildings, and/or long travel distances, especially in rural areas. Many were left to negotiate and deal with these access barriers.

*I've seen some people with disabilities who've never been examined on a table. They've been examined in their wheelchairs. (Community Support Professional)*

### **Adults with ID/DD remaining with their pediatricians**

Due to the shortage of qualified health care professionals who specialize in treating adults with ID/DD, some adults remain with their pediatrician as the only avenue available. Multiple participants from the parent/guardian and community support professional focus groups and some of the health care professional interviewees reported that many adults with ID/DD continue to remain with their pediatricians. One pediatrician reported caring for a patient who was 48 years old.

Some respondents felt comfortable remaining with their pediatricians; however, concerns about getting appropriate, age-related medical care were very apparent. Many respondents raised the question of how and/or when one would transition to adult medical care. Others reported that the transition from pediatric to adult care occurred at later ages, for instance age 27 and 40.

*[My son is] twenty-five. I go to neurology and I sit with babies and I'll say to the neurologist, where should we go? [And the neurologist responded,] Really, you can stay here. The problem is he doesn't know where to send us. Who's going to see this kid? He sees...his orthoped, his GI, everything...at Children's Hospital. (Parent/Guardian)*

Some community support and health care professional respondents highlighted the consequent problems associated with adults remaining with their pediatric physicians instead of transitioning to health care professionals who specialize in adult medicine, including the (a) lack of knowledge of appropriate preventative tests and screenings for adults and (b) lack of proper training about issues related to aging. Some of the pediatrician respondents acknowledged these issues; however, they were determined to do their best and keep the patient until he/she could locate an adult health care professional.

*[A] male with MR [mental retardation] came in with advanced bowel cancer symptoms. [This was] not discovered or acted upon... Do they see doctors preventatively? (Community Support Professional)*

*...we get [patients] referred in to us ... Children's Hospital has a huge adult congenital heart team.... And the patients are kept here at Children's because they're following them into their 30s and 40s. It's unrealistic for pediatric dentists, who really specialize in three year olds and six year olds, to see someone who's 40. There are adult problems, adult gum problems. ...if they're Mass Health, I have no one to see them. (Health Care Professional)*

### **Lengthy waits once health care professionals were obtained**

After the exhaustive search for a health care professional, many participants across all focus groups<sup>3</sup> experienced another obstacle: additional delays. If a health care professional was obtained, many participants described a delay between the date the appointment was scheduled and the actual appointment date. The long waits were partly attributed to the limited number of available health care professionals who were knowledgeable and experienced in ID/DD and adult medicine.

*When a patient reaches 18, I [would] love [to] be able to transition them to an adult dentist who sees adults with special needs and takes MassHealth in Massachusetts. And there is absolutely no one that I have, that I can refer them to. I have tried to refer them to Tufts. New England Medical Center has a grant to provide dental care for adults with special needs and there's a one-year waiting list. (Health Care Professional)*

Lengthy waits caused concern for many respondents. Some expressed frustration because there was no sympathy expressed from the offices of the health care professionals for those who had to withstand unbearable pain for long periods. Others were worried because the medical care needs were further delayed, causing some to question whether the health condition would worsen or not.

*I had severe pain that I woke up four or five times a night for four days in a row. And when I called [the receptionist], I said, I have an emergency wisdom tooth and I found out it's not just a tooth, its part of the actual gum line that's infected as well. ... [I called] some time in June and they wanted me to wait until August 30. (Self-Advocate)*

### **Positive access experiences**

On the other hand, the parent/guardian focus groups varied slightly from the other groups because they reported some positive experiences while attempting to access care. Across two parent/guardian focus groups, respondents reported that positive outcomes were associated with (a) parents' doctors who "picked up" sons and daughters during the transition period from pediatric to adult health; (b) the ease of finding doctors due to multiple insurances, including private coverage; (c) the facilities that predominantly worked with individuals with disabilities, such as Tufts; and (d) doctors who somewhat identified with the families' culture, for example health care professionals who were Latino/a.

*Because my husband and I had the same doctor, he was going to take [our son] on, sight unseen. So that worked out fine... [The doctor] found out [about our son being insured by] Medicaid afterwards and [we] kind of...worked out those kinks too. (Parent/Guardian)*

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<sup>3</sup> Groupings include self-advocate, parent/guardian, and community support professional